Consent to the publication of patient information

Peter A Singer on behalf of the BMJ Ethics Committee

Sometimes valuable clinical information cannot be published because it is not possible to contact patients to obtain consent. The *BMJ* therefore asked its ethics committee to review the guidelines on consent

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BMJ 2004;329:566-8

Information about a patient that a doctor acquires during a professional relationship with the patient is confidential. It may not normally be revealed to others except with the consent of the patient concerned. But does this position admit of exceptions? We argue it does and describe those exceptions here.

Confidentiality

Although the publication of information that enables the patient to be identified is widely agreed to be a breach of confidentiality, the position of anonymised information is more contentious. In one view there is no breach of confidentiality if the patient cannot be identified. Another, stricter, view of confidentiality suggests that revealing anonymised information still amounts to a breach of confidentiality, as it is still revealing details of a private encounter.

Strong reasons exist for preferring the former view. It can be argued that the obligation of confidentiality is restricted to information that is capable of being connected to a particular person. In the absence of such a connection, information simply cannot be confidential. However, any experienced journal editor will recount situations where anonymised information has been recognisable to the patient or family involved and caused upset.

The principle of confidentiality affects the publication in medical journals of any material pertaining to a particular patient or research subject. The policy of the International Committee of Medical Journal Editors on this issue states:

Patients have rights to privacy that should not be infringed without informed consent. Identifying information should not be published in written descriptions, photographs, or pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that the patient should be shown the manuscript to be published.

Identifying details should be omitted if they are not essential, but patient data should never be altered or falsified in an attempt to attain anonymity. Complete anonymity is difficult to achieve, and informed consent should be obtained if there is any doubt. For example, masking of the eye region in photographs of patients is inadequate protection of anonymity.¹

This seems to leave it open to publish information about a patient when it is possible to achieve complete anonymity, even if such cases will be rare.

The UK General Medical Council requires consent to publish patient case studies²:

It is very difficult to anonymise case studies fully, especially if they are of interest because they deal with a rare condition, or the detailed history of a patient with mental illness. Similar problems apply to many photographs.

Did he agree to publication?

For this reason, you must obtain express consent from patients before publishing personal information about them as individuals in media to which the public has access, for example in journals or text books, whether or not you believe the patient can be identified. Express consent must therefore be sought to the publication of, for example, case-histories about, or photographs of, patients.

However, the GMC does admit of exceptions in the case of patients who have died:

You should follow the patient's wishes, if they are known to you. If not, you should consider whether publishing information which could be identified would cause distress to relatives or the patient's spouse or partner.

If you are satisfied that the publication would not cause distress, and that you have no reason to think that the patient would have objected, you may use the case study or photo in published material. You should of course do your best to ensure that the patient is not identifiable from the material you publish.

BMJ policy

The policy of the *BMJ* was stated in an editorial published in 1998.³ This set out a general requirement of consent, followed by a series of possible exceptions in which publication would be permitted without the patient's consent. The exceptions were:

- The patient is long dead and has no living relatives
- The interaction with the patient was long ago—perhaps more than 15 years

- Because the interaction was long ago and the patient was elderly or terminally ill, the patient is likely to be dead
- The piece is to be published without the authors' names attached, making it unlikely that anybody could identify the patient
- All extraneous information that might help identification is excluded
- Even if the patient were to identify him or herself, the events described are unlikely to cause offence.

In practice, these exceptions have not been invoked to allow publication, and several contributions have been rejected because the consent of the patient has not been obtained. Why? Perhaps because these conditions require some operational sharpening and it is unclear whether any or all must apply to justify publication without the patient's consent.

The BMJ Ethics Committee has considered the matter of publishing information from the doctor-patient relationship without consent. The situation commonly arises in "fillers," which are meant to provide thought provoking clinical anecdotes. The committee took the view that a strict application of the consent requirement was excessively restrictive, and we felt that the journal's policy should be re-examined. This view was largely prompted by several cases that came to our attention in which a strict application of the rule would exclude contributions that, on balance, deserved publication. These cases involved patients whose consent was impossible to obtain because they were untraceable.

In order to clarify the situation, the committee has considered the policy set out in the 1998 editorial and approved the revised policy set out in the box:

This policy was pilot tested by two *BMJ* editorial staff in September 2002 on nine cases that had been submitted for publication but that were not published because of lack of consent. Both editors agreed four of these cases met the criteria of the policy, and these were ultimately published:

- A 56 year old case of meningococcal septicaemia in which the patient's life was saved but she ultimately had bilateral below knee amputations; the lesson is that a brilliant clinical diagnosis and prompt treatment does not always lead to ideal patient outcomes⁴
- A 17 year old case in which an ophthalmologist in India put aside personal risk of being robbed to open the door of his residence to a patient⁵
- A 20 year old case about a patient with palatal myoclonus who was initially treated as a psychiatric patient because he complained of a clicking in his head, highlighting the importance of listening to patients⁶
- A case of an appreciative homeless patient, who could not be tracked down, that showed the value of "a hospital providing sick people with a roof over their heads, three meals a day, warmth, and good medical care."⁷

In the other cases, the disagreement between the editors arose from judgments about how worth while was the message, how likely it was that anyone (including the patient) would recognise who it was about, and how likely it was to cause offence or upset if the patient was recognised. On the general experience of using the guidelines, one of the

editors said, "I would say it remains a subjective process but it is useful to have rules to guide our subjectivity."

The committee recognised that publication without consent, using the above policy described, should remain the exception rather than the rule. For this reason, we requested that editors keep a log of the cases published under the policy so they could be reviewed periodically.

We also considered several situations that should be distinguished from publication of information from the doctor-patient relationship as detailed below. These include:

Publication of research results—These arise from the researcher-participant relationship, and are therefore regulated by research ethics committees. Qualitative studies may pose special challenges regarding whether a study participant is identifiable.

Fictional cases—These arise in the imagination of the author and not the doctor-patient relationship. Intentionally misleading the reader by presenting fiction as fact, as in a case about suicide among aboriginal peoples, is not permitted.^{8,9}

Publication of information including photographs obtained from the public domain, including wire services and news archives—This information was obtained from the journalist-subject relationship. The information is in the public domain and it is ethical to republish it in the *BMJ*. Such publication may offend some readers, as in the case of a photo of a young boy with a learning disability published alongside an article on methylphenidate.¹⁰ Editors may want to exercise discretion in publishing such information, but this is a matter of etiquette, not ethics.

***BMJ* policy on consent to the publication of patient information**

1. Publication of any personal information about a patient will normally require the consent of the patient. This will be so even if identifying details are removed.
2. Personal information about a patient will not be published over the patient's refusal, except in the most exceptional circumstance of over-riding importance to public health.
3. Publication without the consent of the patient will be permitted if all of the following conditions are met:
 - (i) The patient who is the focus of the article is untraceable without an unduly burdensome effort and it is also impossible or unreasonable to expect consent to be obtained from the patient or the patient's next of kin.
 - (ii) The article contains a worthwhile clinical lesson or public health point which could not be as effectively made in any other way. (Worth while is intended to sit on a spectrum between "interesting," which is the publication threshold with patient consent, and "over-riding public health importance," which is the publication threshold over patient refusal.)
 - (iii) A reasonable person in the patient's position would not be expected to object to the publication of the case. (This requires an assessment of the intrusiveness of the disclosure and the potential that it has for causing the patient, or the patient's family, embarrassment or distress. Particular attention must be paid to differences of cultural and social attitudes. It must not be assumed that what is a matter of indifference in one society will have the same status in another.)
 - (iv) The risk of identification of the patient is minimised by measures designed to prevent the identity of the patient being revealed either to others or to the patient himself or herself. (These measures will include anonymisation of the case or the author, or both. The publication without consent of photographs will require particularly scrupulous attention to anonymisation.)

Data relating to aggregate anonymised tissue and other samples—These will not normally be considered to be personal information relating to a particular patient, and publication of research findings connected with such samples does not require patient consent.

Genetic pedigrees—These represent a special problem. The committee is preparing a paper on this.

Medical error—One particularly intriguing type of case is medical error. Consider, for example, a recent published case report on “wrong side” surgery.¹¹ The surgeon is at greater risk than the patient in relation to publication of this information. Publications about error should be encouraged as they are core to improvements in patient safety in both relation to analysis of root causes and engendering a culture of openness about error. If a patient refused consent to publish, perhaps because of anger at the physician, should that preclude publication? If you might publish even if the patient refused, should you even ask permission?

Conclusions

The objective in revising *BMJ* policy on consent to the publication of patient information was to ensure the protection of patient confidentiality while at the same time seeking to facilitate the serious communication of medical information. In clinical practice confidentiality is not an absolute principle but admits of exceptions—for example, the duty to warn—and it should therefore come as no surprise that confidentiality is not absolute in editorial practice either. The policy set out above should afford adequate protection for confidentiality without making informative exchanges impossible. Our position recognises that ethics is rarely about absolutes: context matters, and judgment is essential.

Summary points

Publication of data arising from the doctor-patient relationship normally requires consent

In a few circumstances publication can be justified without consent

The *BMJ* has revised its policy to clarify these circumstances

The current members of the *BMJ* Ethics Committee are Iona Heath (chair), Andrew Lawson, Asad Raja, Peter Singer, Ann Sommerville, Jeffrey Tobias, Derick Wade, Elizabeth Wager, and Tom Wilkie. Richard Smith also attended meetings. Alexander McCall Smith chaired the committee from 2000 to 2003 and drafted this article for the committee with PS. We thank the *BMJ* editors who participated in the development of this policy, especially those who pilot tested it. Rachel Fetches provided valuable help to the committee in preparing this article.

PAS is a distinguished investigator of the Canadian Institutes of Health Research.

Competing interests: None declared.

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(Accepted 2 June 2004)

Barbara's bowel

Four inches of snow and my hilltop home is cut off, so, one snowy day, I swapped a radiological session at my base hospital for a session at a local cottage hospital just two miles down the hill. No sooner had I set out to walk in boots and anorak, than a Landrover driven by a gentleman farmer stopped, and I was offered a lift. His passenger was my neighbour, Barbara, an elegant professional lady whose vitality and sophisticated charm guaranteed her popularity, particularly among the local gentry. As we inched down the icy Cotswold lane, I was pleased to learn that Barbara, conveniently for me, was also heading for the hospital to keep an appointment. Indeed, that is why she had enlisted the help of her friend with his four wheel drive vehicle. However, my pleasure quickly changed to disquiet when I learnt that Barbara was to have a barium enema, and I knew I would be the radiologist assigned to perform it.

We all prefer examinations to proceed with Germanic efficiency in sleek modern surroundings, particularly if the patient is a friend and the procedure a delicate one. But it wasn't like that. The local x ray equipment was on its last legs, and the department was just about to be refitted and redecorated. Radiological reporting was carried out in the tiny radiographers' coffee room just beyond the toilet outside the x ray room, and dictation had to be quiet enough to be inaudible to the patient in

the toilet next door. The environment was decrepit, and some examinations almost sordid. To add to the problem, Barbara had a lengthy, tortuous colon, and—despite turning, twisting, and compressing her—barium and air would not pass proximal to the hepatic flexure. Eventually, after a protracted and messy examination, I had to settle for suboptimal, single contrast views of the caecum.

The only comforting news that morning was that no other patient was able to get to the hospital. All had telephoned to cancel their appointment. Consequently, as Barbara left the department, I departed with her. Her farmer friend looked less than happy after the unexpected wait but, nevertheless, generously offered me a lift back up the hill. I returned to the comfort of the fireside, Barbara having been my only patient of the morning.

Barium enemas are no longer performed at the cottage hospital, and the radiology department has been refurbished with new equipment. From time to time, I see Barbara around the village. She is always charming and cheerful, but, having spent over an hour looking at her bowel, I find I can no longer look her in the eye.

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